

# Nonverbal Learning Disabilities

*What kind of communication challenges do parents face when communicating with their children with nonverbal learning disabilities, and what kind of strategies do parents use to overcome the challenges?*

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## **Abstract**

**Title:** What kind of communication challenges do parents face when communicating with their children with Nonverbal Learning Disabilities, and what kind of strategies the parents use to overcome the challenges?

**Research Question:** What kind of communication challenges do parents face when communicating with their children with Nonverbal Learning Disabilities, and what kind of strategies the parents use to overcome the challenges?

This is a qualitative study that explores and tries to understand what kind of communicational challenges do parents face when communicating with their children with Nonverbal Learning Disabilities, and to comprehend what kind of strategies these parents use to overcome these challenges.

The designation of the Nonverbal Learning Disabilities (NLD) was formerly proposed by Johnson and Myklebust. NLD were firstly described by Myklebust as an inability to read and understand nonverbal aspects of one's environment. (Myklebust, 1975)

Children with nonverbal learning disabilities struggle to make sense of all the nonverbal cues present in our communication. These children may totally misunderstand nonverbal communication or, they can understand it but are unable to give an appropriate reply.

For this study I will present the challenges of a couple of parents when communicating with their child with NLD, and the strategies used by the parents to overcome the challenges.



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# **1 Introduction and background**

This study is a qualitative research about communicational challenges between parents and their children with nonverbal learning disabilities (NLD), and strategies used by the parents to overcome these challenges.

The study explores and tries to understand what kind of communicational challenges do parents face when communicating with their children with Nonverbal Learning Disabilities, and to comprehend what kind of strategies these parents use to overcome these challenges.

Communication is a vital part of our existence. It is through communication that we relate as human beings, transmit intentions, share feelings and are able to establish trustful, cooperative and meaningful relationships. This communication happens verbally but also through nonverbal cues (facial expression, eye contact, tone of voice, body posture and motions), an estimated 65% of our communication.

Children with nonverbal learning disabilities struggle to make sense of all the nonverbal cues present in our communication. These children may totally misunderstand nonverbal communication or, they can understand it but are unable to give an appropriate response.

This fact can make social interactions difficult and produce high stages of anxiety and unhappiness.

## **1.1 Purpose and outcome of the Study**

The purpose of a study explains *why*, in terms of wider significance, is the study carry out.

The purpose of this study is to understand what kind of communicational challenges may arise between parents and their children with NLD. It is also the purpose of this study to explore what kind of strategies parents use in order to overcome these challenges. In addition, this study can also add understanding about Nonverbal Learning Disabilities concerning the communication area throughout real experiences lived by children with NLD and their parents.

The purpose of a study is connected to the question to which the researcher is going to answer. According to Bogdan & Biklen, 1998, the goal of qualitative research is to “better understand human behavior and experience...grasp the processes by which people construct meaning and to describe what those meaning are” (p.38)

The purpose of this study is to show real examples of several different communicational challenges between parents and their children with NLD and to show the parent’s strategies in order to rise above these challenges and be able to find a way to have a more functional and effective communication.

In addition, the purpose of this study is also to show what kind of communicational challenges and strategies parents use when communicating directly with the child and when acting as translators between the child and other people.

The outcome of a study refers to what the research is aiming to achieve with the study. Richards (2005), defends that it’s useful to write about the outcomes of a study in a early stage, because “in many ways this will inform your design”, indicating the data extent “needed to represent all the views on a problem”. (p. 13)

The outcome of this study will be to make a real contribution to the field of special needs education concerning the Nonverbal Learning Disabilities syndrome.

Children with NLD are extremely verbal, the communication area is often forgotten and ignored. However, these children struggle to understand and to be understood in everyday situations (despite their verbosity, which is not as functional as might seem).

## 1.2 The background of the Study

My own background as a special needs teacher guided me to recognize communication as the most important tool to assess children with special needs education.

Communication plays a central and vital part in our nature as human beings. It is through communication that we define ourselves to the others and it's also through communication that we perceive the world, when trying to decode the complexities concerning our reality.

Communication is also our tool when sharing knowledge. Our knowledge as individuals (personal experiences, opinions, etc.), but also our knowledge as social beings: the knowledge about living in society. It will be through communication that a new born will learn in few years the two millenniums of what it is to live in society. This fact assumes that language, as social perform, exists before any of us are born, being described, by Merleau-Ponty (1962), as a "pre-reflective bond": humans are bonded by a pre-linguistic empathy basically due to the own fact of our existence.

Children with learning disabilities, who show challenges when producing and / or processing verbal or nonverbal information, can easily find themselves in challenging situations concerning their individual and social development. Kutscher (2005), defends that

People do not "over-react". Instead, they "over-feel". When a child blows up over what seems like a trivial issue to us, it may help us to understand that in this child's mind, the issue must have a tremendous amount of meaning. (p.28)

Recently there has been a focus in studying the communicational aspects concerning children, young's and adults with NLD.

Because their lack of skills concerning the pragmatic use of communication, children with NLD can find themselves lost among the innumerable meanings of communication. Kutscher (2005) defines the pragmatic use of language as the "practical ability to use language in a social setting, such as knowing what is appropriate to say, where and when to say it; and the give and take nature of conversation." (p.88)

These children, and because of their difficulty in reading/interpreting nonverbal information and because of their lack of spatial skills, have the need to get the world translated in a verbal way.

This verbal information, however, must be done in a very concrete and clear way in order to minimize/avoid possible confusions for the child.

Their literal way of understanding the world, the lack of ability to read nonverbal information and their, many times, social inadequacy, can lead them to high states of frustration and suffering.

At the same time, one of the strengths of these children it's their verbosity and their rich vocabulary, often superior to children in the same age rate. This fact can be one of the explanations why language is often a neglected area of their neuropsychological profile (Humphries, Cardy, Worling and Peets, 2004) Though their verbal abilities are one of their strengths, these are not functional when it comes to process the information received leading to a poor literal way of understanding reality.

The parents of children with NLD play a vital role when verbally describing the world. They act simultaneously as mediators between the surrounding world and their children but also act as mediators between the child and other people.

Communication is like a bridge that connects us to others, and the parents have a crucial role in being the *translators* to these children. However, also the parents face challenges when trying to understand and/or trying to explain something to their children. Overcoming these challenges through the use of strategies seems to be the first step to provide these children the opportunity to make sense of the multiple surrounding contexts.

The first time that I heard about NLD was through the words of parents who shared with me several communicational challenges between them and their children with nonverbal learning disabilities.



As a special needs teacher, I have had the chance to interact with these children's parents and to listen to their opinion, happiness, hope but also worries. Most of these worries reflect the permanent challenge in trying to communicate with these children in a way so they can understand what is happening around them in an easily, less confusing, way.

Later, the exceptionality about this syndrome and at the same time the little knowledge that teachers and health people seem to show about it turned on my attention and dedication for this theme. When working as a special needs teacher at my home country I had the chance to experience that, very often, intervention programs look promising, these tend to fail due to the lack of knowledge about specific disabilities.

Nonverbal Learning Disabilities is a long life condition which will affect individual and social areas, having serious repercussions on the quality of life of people with nonverbal learning disabilities. Contrarily to other disabilities where people show a natural tendency to isolate themselves, people with NLD don't aim (in a first instance) to be alone. They aim for friends and social interaction; however the typology of NLD can make this a big challenge and therefore generate soreness and unhappiness.

In order to improve the quality of life of people with NLD it is necessary more research about the theme. This research will be a consolidation of the acquired knowledge and also a starting point for future studies in this area.

According to all that was mentioned above about communication and NLD, and my own motivations, I ended up with the following research problem:

### **1.3 Research problem**

What kind of communication challenges do parents face when communicating with their children with Nonverbal Learning Disabilities, and what kind of strategies do the parents use to overcome the challenges?

This study is divided in 5 chapters:

### **3. Structure of the thesis**

#### **Chapter 1: Introduction and background**

Chapter one provides the introduction about the study and the background. The background about the study focus on human communication in order to contextualize and locate the challenges that NLD may bring concerning communication and interaction. My own motivations for this research are also mentioned within the background of the study.

The chapter ends up stating the purpose and outcome of this study.

#### **Chapter 2: Theoretical framework**

In this chapter I focus on the Nonverbal Learning Disabilities characteristics, their connection and how these are reflected in children's behavior with NLD. The aim is to provide an overview of the most important strengths and deficits about NLD and to provide an understanding how these characteristics interact being simultaneously cause and consequence.

This chapter also sets out the conceptual framework of my thesis: I discuss the theories and concepts which are useful to conceptualize the research. The theoretical framework is the angle from which I am approaching my topic. It presents the theory which explains why the problem under study exists.

### **Chapter 3: Methodology**

This chapter will show my reflections, as meticulous as possible, about the process of data collection and data analysis. I will explain how the study was conducted, reflecting upon the several steps that I decided to take, such as, for example, the choice of the methods and techniques present in this research, but also my reflections upon the challenges that crossed my way. This chapter is basically analytical. It contains detailed analysis of my research methods, why I chose them, what they guided me to find, and what conclusions I have drawn from that process.

### **Chapter 4: Presentation of the results**

This chapter reports and summarizes the results of research obtained through the methodology. I include the statements of the parents ensuring that these are presented in relation with the research problem of the study, and that this selected data reflects its original context.

This data will support the conclusions and discussion on the last chapter.

### **Chapter 5: Discussion, and the overall conclusions of the research**

In this chapter I state what I have been done and what I found from my study. The aim isn't only to describe the results, but also to make connections and present in a clear way why my data should be interpreted in one way rather than another. The aim is also to discuss what these findings mean in relation to the theoretical body of knowledge in connection to my profession.

These conclusions show the significance of the research for knowledge in the discipline of Special Needs Education. I will also discuss the limitations of the study.





## **2. Theoretical framework**

This chapter presents the main characteristics of nonverbal learning disabilities and their interrelation. It will be presented the main deficits and how one deficit can be at the same time cause and consequence. It will be also presented the main strengths of nonverbal learning disabilities.

The chapter ends up presenting the main theory of the study.

### **2.1 Nonverbal Learning Disabilities (NLD)**

The concept of nonverbal learning disabilities is distinguished from learning disabilities where language functions are mainly affected. Nonverbal learning disabilities can be viewed as the result of the difference between the brain development and brain function. (Hahn, 2004)

NLD children present major challenges in acquiring and using age-appropriate skills, regardless of normal capacity to learn and appropriate opportunity.

The designation of the Nonverbal Learning Disabilities was formerly proposed by Johnson and Myklebust. NLD were firstly described by Myklebust as an inability to read and understand nonverbal aspects of one's environment. (Myklebust, 1975)

In the early 1970s, it began to be widely studied by Byron Patrick Rourke, through the study of children who showed important inconsistencies between their verbal and nonverbal IQ scores. These inconsistencies mean that there is a difference / discrepancy between the "verbal, language-based cognitive skills and nonverbal, visual-spatial cognitive abilities in these children." (Roman, 1998, para.15)

This is considered to be one of the most recognized features of NLD: a significant higher verbal IQ score than Performance IQ score on formal measures of intelligence. (Johnson, 1987; Weintraub & Mesulam, 1983)

These results served up the development of the first model in order to “provide a heuristic framework for the investigations that would follow. The focus of this model was the developmental and task-related differences and interactions between right – and left – hemisphere systems.” (Rourke, 1989, p. 59)

Rourke’s “white matter” model (Rourke, 1982, 1987, 1989, 1995; Rourke, van der Vlugt & Rourke, 2002) was based in hemispheric differences proposed by Goldberg and Costa (1981): the dysfunction in cerebral white matter, the long myelinated fibers thought to be responsible for association and assimilation of cognition (Fisher, DeLouca, & Rourke, 1997).

According to Stewart (2002),

*A neurological disorder is a neurological dysfunction in the way in which the brain processes information. Such a dysfunction is inherited: it comes with the child. It is not a retardation of any type, but a difference in cognition or thinking that creates difficulties in understanding the world an interacting with others. (p.4)*

The findings about NLD (Rourke, 1989), were grouped in neuropsychological deficits.

## **2.2 Neuropsychological Deficits**

Neuropsychological deficits were divided in primary (simple motor skills, auditory perception and rote material), secondary (attention), and tertiary deficits (memory), verbal (speech and language), and academic deficits.

Between these deficits there is a cause-effect relationship, meaning that primary neuropsychological deficits are considered to lead to the secondary neuropsychological deficits, and so on throughout the all the dimensions.

Academic and socio-emotional / adaptational dimensions are seen as essentially as consequences: as dependent variables of these neuropsychological deficits. (Rourke, 1995).

### 2.2.1 Primary deficits

Human communication and interaction requires more than the use of words. When communicating, human beings play a multipart game of facial expressions, body movements (gestures), posture, gaze, and use words which must match with the context and with the receptor. These primary deficits comprehend tactile and visual perception, complex psychomotor coordination and novel material.

Problems in interpreting nonverbal information, such as facial expressions can lead to inappropriate interactions regarding the content and time when these ones occur. At the same time, the difficulty to adapt to new material, will lead the child to a situation where it can be extremely difficult to succeed in interpersonal interactions. (Volden, 2004)

Research (Cornoldi, Rigoni, Tressoldi and Vio, 1999), indicates that children with nonverbal learning disabilities scored lower, than their colleagues without learning disabilities, in all tasks comprehending the use of spatial and visual skills.

Social relations can be severely impaired due to the lack of these “antennas”. Difficulties in recognizing facial expressions (happiness, sadness, anger, etc.), challenges in understanding the sequence and relationships of episodes, can lead to major difficulties for children to see the world as series of interrelated events.

Rubinstien (2005) points out that “...visual-spatial deficits make it difficult for affected people to decode nonverbal signs, such as recognizing faces, understanding expressions that indicate certain feelings or emotions, and reading commonly used cultural signals used to communicate specific messages.” (p. 35) These deficits tend to increase with age.

Motor skills both gross and fine can be a big challenge for these children. To be able to manage a knife and a fork at the same time or to kick a ball can be quite challenging and not always achievable. They have poor coordination skills (more clear on the left side of the body) which will reflect also in the social skills: during childhood, because of their lack of motor skills it is common for these children to be aside of the games during break time at school.

Children with NLD also show evident difficulties in coping with new situations, even when sometimes, these new situations are positive (a good surprise, a good event, etc.). Stimulus configurations which are novel are difficult to accept and accommodate: these children show difficulty in appropriating a response to a novel situation or an unfamiliar context. (Telzrow, & Koch, 2003).

### **2.2.2 Secondary deficits**

Attention and exploratory behavior are considered NLD's secondary deficits. The use of selective attention works much better for straightforward, repetitive material which is delivered through auditory modality. Attention to visual and tactile material is poor. Complex and nonverbal material are difficult to interpret by these children. This fact has a direct influence on the exploratory behavior: children with NLD tend to show a reticent behavior when exploring the world around them. This aspect is believed to be a consequence of their reduced lack of aptitude with tactile and visual input. (Rourke, 1989).

A NLD child can be viewed as a *verbal explorer*; contrarily to other children, they explore the world through objective questions about the aspects they wish to understand. Verbal information given by others is the way these children collect experiences and organize their knowledge. (Burger, 2004)

Rourke (1989) adverts that one of the primary strength of these children, the dominance of the auditory over the visual when processing information, is the actual explanation of why these children prefer to hear about the world instead of going out to see it and touch it. These children are, therefore, better "auditory learners" than "visual learners." These primary and secondary deficits cause tertiary deficits.



### 2.2.3 Tertiary deficits

Tertiary deficits comprehend memory, concept formation, problem solving, strategy generation, and hypothesis testing; appreciation of informal feedback.

All these areas show visible challenges particularly if it's a new concept or a new problem to solve. The difficulty in dealing with appreciation or informal feedback makes these children show difficulty accepting criticism (Badian, 1992), and makes them being described by others as “socially immature” (Johson and Myklebust, 1960).

The lack of exploration of the world through visual and tactile skills will lead to difficulties on formation of concepts and problem solving: few environmental impressions will reflect on a poor capacity in understanding situations and places using logical reasoning and problem solving as methods. (Molenaar-Klumper, 2002)

According to Rourke (1995), “these children remain essentially sedentary, exploring the world not through vision or locomotion, but rather through receiving verbal answers to questions posed about the immediate environment” (p.8).

Rourke suggested that the primary and secondary deficits in adaptableness and dealing with novel situations result in poor explorative behavior meaning that these children will struggle with difficulties in concept-formation, problem-solving and causal relationships. These problems in exploring the world in an active way will restrict their view of the world.

The information that these children have about the surrounding reality is restricted by verbal exploration alone, lacking the sensor – motor input. (Volden, 2004)

### 2.2.4 Verbal deficits

Verbal deficits refer to speech and language. NLD children have several challenges when concerning the use of language. Their biggest challenge happens when processing information; these children can't *read between the lines*, all information is processed in a very factual and objective way.

According to Stewart (2002)

These children interpret language literally, often missing sarcasm, humor, or even threats. The facial expressions and changes in the tone of voice that convey the meaning in such statements are missed by these children, who rely on the literal meaning of the words to understand the communication. (p.27)

Words can have several ambiguous meanings, and this becomes a challenge for these children. Our communication is based in meaning that we give to things, situations, and it's also based in the meaning that we construct together as a characteristic of human behavior.

Concepts as "justice", "love" are difficult for these children to understand due to the several meanings and perspectives that these words contain.

Humor is one of the areas of our communication which brings several challenges for NLD children. Often humor relies on subtle indirect meanings where the ability to perceive and decode these ones is crucial. Mamen (2007) defends that these children don't have to be necessary humorless: these are capable of laugh of situations that represent physical humor, concrete situations where what happens is direct and obvious, instead of those that require skills to decipher and interpret hidden or subtle messages.

According to this, research (Semrud-Clikeman and Glass, 2008) shows that children with NLD have challenges with humor comprehension due to poor social perception, but not necessary directed related to visual-spatial perception.

Also, according to Stewart (2002), "They produce language that is accurate but not functional. This language conveys information but fails to establish connections between the children and others. They understand the content of the words but often miss the emotional implications language can have." (p.48)

Human communication is also about words that we don't say and about what others think that we mean. We have the ability to imagine what others are thinking even though they don't tell us. A typically developing child is able to understand all these components and their interrelation and soon learns how to behave in these contexts and how to adapt and react to them.

### **2.2.5 Academic deficits**

All the components present in NLD will result in significant deficits also concerning the academic area. This area comprehends graph motor, reading comprehension, mechanical arithmetic, mathematics and science.

Children with NLD often show difficulties in comprehending inference in a conversation but also in a text. They fail to understand the messages *between the lines* and the metaphors used. (Worling, Humphries and Tannock, 1999)

According to Foss (1991), children with NLD tend to focus on the details losing the holistic picture of a situation. This situation can lead to difficulties in problem solving because the cause-effect visualization might be insufficient to an appropriate inference and consequent decision. In the same way, recent research (Schiff, Bauminger, & Toledo, 2009) shows that NLD children show challenges in processing and transferring knowledge to new similar situations.

Students with NLD demonstrate difficulties in reading comprehension because of this lack of being able to produce a conceptual framework for relationships and patterns of ideas connecting the several variables. (Chow and Skuy, 1999)

Research done by Rourke and Fuerst (1995) showed that the same nonverbal deficits present in their cognitive and academic challenges are responsible for the deficits in their social insight.

### **2.2.6 Socioemotional/adaptational deficits**

This is one of the most debilitating, and challenging, symptoms for children with NLD. These children struggle with adaptation in novel situations, social competence, emotional disturbance and activity level.

The NLD symptoms don't confine themselves to childhood. Their difficulty in interpreting social cues and interpersonal relation behavior's, can lead them to feelings of rejection and social exclusion. (Rourke, 1989; Martin, 2007).



NLD has a long-life character that will affect them academically, vocationally, socially and emotionally. (Hornik, 2007)

Social skills allow us to perceive and understand several situations when interacting with others. Nonverbal information (facial expressions, gestures...) give us important information about the person/people who we are talking to. These nonverbal signs also help us to *regulate* the content of our conversation and to adapt it according to the feedback that we receive from other people.

An estimated 65% of the meaning in a social conversation is communicated nonverbally through facial expressions, eye contact, tone of voice, gestures, etc. It becomes extremely difficult for these children to decipher and interpret this type of communication. According to Brumback, Harper, and Weinberg (1996), "Lesions of the right hemisphere produce (...) difficulties producing or recognizing the tone, pitch and melody of speech associated facial expression, posture and body gestures." (p. 427)

Petti, Voelker, Shore and Hayman-Abello (2003) point out that "It is theoretically consistent that children who struggle with visual-perceptual organizational tasks would have difficulty interpreting often subtle and fleeting nonverbal social cues, such as facial expressions and various paralinguistic sources of important social information." (p.24)

Palombo in 1996 also pointed out that because nonverbal learning disabilities affect the area of visual-spatial procession of information, and areas associated with reception, expressing and processing of efficient communication, these factors will make the child experience the world in a different way that others experience it, and this can lead the child to high self-esteem problems.

In addition to this, children with NLD also show difficulties in understanding other's emotions and their own. (Hahn, 2004)

Research (Dimitrovsky, Spector, Levy-Shiff, and Vakil, 1998; Petti, et al., 2003), shows that children with nonverbal disabilities scored lower compared with children with verbal disabilities when deciphering emotions of others.



All these conditions are, in agreement with Rourke (2005), a fertile soil to the development of a typical pattern of psychopathology characterized by anxiety, depression, atypical behaviors and in late instance, suicide risk. Studies done by Rourke (2000), and his colleagues, reveal that there is a strong relationship between children with NLD and an increased, and growing with the age, risk for severe psychopathology of an internalizing nature. Research (Ellison & Semrud-Clikeman, 2007; Gross-Tsur, Shaley, Manor and Amir, 1995; Nowicki & Carton, 1997; Rourke, 1995; Rourke, Young, and Leenaars, 1989), shows that these factors can lead to withdrawal and social isolation, and that in last instance can lead to suicide. According to these researches, the incidence of depression and suicide among children and adults with NLD is elevated.

## **2.3 NLD strengths**

### **2.3.1 Basic verbal and expressive and receptive language skills**

When it comes to verbal communication, these children show a good domain of verbal skills: quite often these children show a rich vocabulary, superior, to a certain extent, to children in the same age rate without NLD. According to Stewart (2002), they demonstrate very good performances in their articulation, verbal output, auditory perception, vocabulary and verbal memory<sup>1</sup>.

Research (Casey & Strang, 1994; Rourke, 1989) indicates that the strengths comprehending basic verbal skills, including memory and use of syntax have been described to be as functional as children without NLD, though these children can show some delayed language development when it comes to semantics, prosody and pragmatics (Rourke, 1989; Rourke and Tsatsanis, 1996).

Despite their ability to decode a text, for example, it's challenging for these children to comprehend what they are reading because the difficulty in organization and higher level reasoning.

These challenges concerning the use of functional abilities to process information can also be noticed when the child struggles to distinguish important information from non-important: for

---

<sup>1</sup> The capacity to remember verbal information

a NLD child every piece of information holds the same importance, being difficult, therefore, to prioritize or to focus on the important details.

This can also lead to difficulties when trying to find and relate causes and consequences.

### **2.3.2 Auditory processing skills**

NLD children show exceptional retention of material/information presented orally, however they are not always able to assess and process all the information in an effective way. They often miss that information that it's not clear and which plays with the ability to decipher certain nuances.

Because their highly developed rote memorization skills, these children can easily memorize mathematic rules, but they struggle when applying this information into given assignments and when applying this knowledge into new given tasks.

## **2.4 Theoretical framework and Symbolic Interactionism**

A theory can be seen as a set of prepositions about the connection between several concepts or ideas, meaning that different frameworks will guide the attention to different aspects of the phenomena under study.

It's this direction (the theoretical framework that the research will choose among from all the possible choices – psychoanalytic, symbolic interactionism, etc - that will shape the focus of the research and the choice of the method and techniques. (Liamputtong and Ezzy, 2005)

According to Bogdan and Biklen (1998) “Whether stated or not, all research is guided by some theoretical orientation. Theory helps data cohere and enables research to go beyond an aimless, unsystematic piling up of accounts. (p. 33)

The general theory-base of this study is Social Interactionism. This sociological Paradigm carries under its umbrella the Symbolic Interactionism sub perspective which will be the specific theory of this study. According to Blumer (2004) “Symbolic interaction is unique in that the participants respond to each other’s actions on the basis of the “meaning” of these actions.” (p. 37)

### **2.4.1 Symbolic Interactionism**

This theory is based on the work of George Herbert Mead (1863-1931), and defends that is through the process of communication that people construct meaning about reality. Contrary to behaviorists who defended that only the observation of behavior could explain behavior, Mead believed that meanings and symbols are extreme important when trying to understand and describe human behavior.

Symbolic Interactionism focuses the dynamic interaction between people and the interpretations that human beings do about everything. (Charon, 1989; McCall 2003) It is through this interaction that human beings assimilate and process information about reality, trying to make meaning about the several subjective aspects of it.

This theory defends that the words used in our communication are symbols, that these words have a meaning, they stand for something. Words aren’t empty: they have a meaning and that meaning is social; is created and understood in society. Words aren’t only a representation of a physical object, but they carry an all set of meaning and values given by us.

Symbolic interactionists defend that we react always to a meaning and not merely respond to a stimuli (Hewitt, 2003)

According to St. Clair (1982),

Symbolic interactionists assume that the social world they have constructed consists of commonly shared symbols which they have learned from the significant others in their lives. These self images are important in determining just what a person will do in a given context. (p. 223)

Our perspective about the world is shaped through the way we perceive the information and what meaning we give to that same information. This information will be organized in systems, created by us, that settles our view of the world and ourselves. (Bedell and Lennox 1997)

The way we organize this information will reflect on the way we respond to reality, according to the meaning that this information has for us. Charon (1989), states that

As we interact we develop a perspective as to what is real and how we are to act toward the reality. This interaction that gives rise to our reality is symbolic – it is through symbolic interaction with each other that we give the world meaning and develop the reality toward which we act. (p. 54)

Symbolic interactionists argue that our experiences are constructed throughout successively constructions of meaning resultant of our more individual experiences but always together as human beings. Together we create, transform and share meaning. This meaning will always be social, because its conception derives from our social interaction as human beings. Hertzler (1965) concludes that “This assigning of meaning is a *necessary* human activity: without it, no experience has existence or reality.” (p. 26)

Children with nonverbal learning disabilities struggle to make sense of a big part of all the information that they receive. One of the challenges is exactly to make meaning, to give meaning to all these information.

Symbolic interactionism tells us that when these children struggle to decode information, we need to be aware that this challenge acquires a social dimension and evolves us all while creators of meanings; in agreement with Turnbull & Turnbull, (1986) “Communication problems reside in the interactions between people, not within people.” (p. 27)



### **3. Research Methodology**

#### **3.1 Reflections upon the process of data collection**

This study was initially designed to be a qualitative research about communicational challenges between children with NLD and their parents. After discussing with my adviser which the number of cases that would be more appropriate, it was decided that 3 cases would be the most suitable.

My key-informant, and also my only participant, had a very important and active role when connecting to other parents of children with NLD. Her net-work would be very useful to find other parents willing to participate in this study.

I knew from before my key-informant, and it was because of being in touch with her and her son with NLD that I decided to write my thesis about this syndrome. The fact that we are both Portuguese had a relevant role: the non-existence of language barriers and the share of a same culture brought us close.

I developed, previous to start writing this study, a straight relation with her soon. And, also here, developing a friend relationship with this boy, made me feel that this theme would be the most interesting to write a thesis about. By this point, I had decided that I would write my thesis about Nonverbal Learning Disabilities.

After this initial phase, it was decided that my key-informant would be one of the participants and that, with her help, we would find 2 more couples. After my key-informant had been in touch with some parents, I received positive answers from these ones.

I tried to transmit to these parents that this study would be a team work about a syndrome that is yet not familiar to a lot a people and that we would be working together to a common goal, being both parts active agents in the interview, searching for a common meaning, against the perspective of Scheurich (1995) who states that “Interview interactions do not have some essential, teleological tendency toward an ideal of ‘joint construction of meaning’ ... Instead, interactions and meanings are a shifting carnival of ambiguous complexity, a moving feast of differences interrupting differences.” (p. 243)

However, from all the four couples who were contacted, I got response from only one who asked for a confidentiality declaration in order to participate in the study. This declaration was sent as soon as possible. After this, I didn't receive any more contact from this couple.

The first two couples were contact and these were extremely positive when talking to my key-informant. After trying to contact them and not receiving any answer, two more couples were contacted. Also these two couples, who seem enthusiastic when my key-informant contacted them, decided not to participate. Also here I didn't receive any explanation why.

I do need to confess my initial optimism was now influenced by these episodes, but my choice about researching about NLD was never in question.

Contrarily to what I was expecting for, none of the couples decided to participate in this research. The reason why I was so optimistic, and despite the language barriers, was that we would be working for a common goal: to generate and transmit knowledge about NLD through their experiences. Just like Wiles, Charles, Crow & Heath (2006) state:

A second important feature relating to the social context of consent concern's people motivation for participation in research. Study participants in social research often choose to participate on the understanding or hope that their experiences will 'help' others in a similar situation. (p. 296)

After reflecting upon these occurrences, and in the need to find myself an explanation, I thought that these might be three possible reasons: language barriers, the parents as the "working-material" and the fear that, somehow, their answers would be compared to each other in "more or less" good strategies.

Concerning the potential first reason, it is possible that language barriers were one of the causes why these parents decided not to participate. It was explained on the letter that the interviews would be conducted in English.

The possible second reason has a direct connection to what we *usually* expect from a study in the special educational needs: in this field it is common that we work directly with those who show the "special need", those who show the disadvantage (the social aspect of disadvantage) towards the rest of the population. It is possible that these parents expected, before getting the letter that the children were going to be the ones interviewed.

The last possible explanation has to do with the fact that the parents might have felt that, and because they were the ones to get interviewed, their answers could be somehow compared to each others. That there was were “wrong” or “right” answers.

It was always present in my mind that it was extremely important to explain that it was never the intention of the study to compare these three experiences. Each experience would be a history by itself; it would never be the purpose of this study to compare these experiences into more or less effective strategies when communicating with the children.

After these incidents, I tried to conduct this study in the best way possible in order to guarantee its validity and significance. The next pages illustrate the process of data collection and analyzes.

### **3.2 Qualitative Research**

Qualitative research can be described in a simple way as social research which is not based on numerical data analysis but which relies on text data trying to understand the meaning of human action instead for converting it to numbers. (Schwandt, 2001).

Many claim that qualitative research can't be reliable due to the lack of clear rules. Positivist's researchers have defended that because of its nature, qualitative research is not reliable or valuable having a very small contribution to scientific knowledge in general and health care in particular. (Baum, 1995; Denzin and Lincoln, 2000; Guba and Lincoln, 1994).

However, the nature of qualitative research shouldn't be analyzed regarding the accuracy and reliability put side by side with quantitative research. The focus, the aim is just not the same: qualitative research's focus is on the experience of the people as authors of their own history. It's their experience, their views, therefore their perspectives and feelings.

This focus on meaning and interpretation provide us a very rich description about one's views and the essence of their experience. Their feelings, experiences and opinions will be the working material for the qualitative research. According to Bateson (1972), qualitative researchers can be regarded, in part, as philosophers, in the way that “universal sense in which all human being... (is) guided by highly abstract principles”. ( p.320) In the same way, Denzin and Lincoln (2000), defend that all research is interpretative, in the way that “it is



guided by a set of beliefs and feelings about the world and how it should be understood and studied. (p. 19)

According to Liamputtong and Ezzy (2005, p.14), there are three interconnected questions that need to be taken into consideration in the start of a qualitative study:

1. What is the theoretical framework within which the study is being conducted?
2. What is the substantive issue being research?
3. What are the desired outcomes of the research?

These two researchers claim that even though these three questions need to be clearly addressed, the order in which the research decides to follow and will respond to them, will be in part connected to the goals of the research.

Denzin and Lincoln (2000), resume qualitative research to “a situated activity that locates the observer in the world. It consists of a set of interpretative, material practices that make the world visible.” (p. 3)

Intrinsic to what is going to be research about and how the process will occur, is the choice of a qualitative approach. A qualitative approach is a common way of thinking about conducting a certain study. It will describe, more or less explicitly, the purpose of the study, the role of the researcher and the methods choose.

This study, because it aims to understand the phenomena through the experiences of parents of children with NLD, is a phenomenological approach of reality.

### **3.3 Phenomenology**

Phenomenology is a school of thought that highlights a focus on people’s subjective experiences and interpretations of the world. Meaning that phenomenologist wants to understand how the world appears to others, through their experiences.

The purpose of phenomenology is to understand the phenomena from the viewpoint of those who have experience it. The aim will be to understand the phenomena through the eyes



of the participants, to understand the meaning they have given to the experience, and try to comprehend the core of the phenomena as they experience it. (Collingridge & Gantt, 2008)

In a phenomenological study, the researcher is intimately connected to the topic under research..

Husserl (1931), the founder of phenomenology as a philosophical movement, writes the following procedures when using and conducting a phenomenological study:

- 1- Identify a topic of personal and social significance;
- 2- Select appropriate participants;
- 3- Interview each participant;
- 4- Analyze the interview data

According to this author, when choosing the study topic, the researcher should feel both intellectually and emotionally connected to this one.

When I choose NLD as my research topic, I was already emotionally connected to this area and was willing to make some contribution within this theme. Nevertheless, NLD is a theme of social relevance; it is unfortunately unfamiliar to several parents and teachers, and the consequences for children with NLD can be overwhelming.

When it comes to the selection of the participants, it's vital that they have experience with the phenomena under study. It is through the experiences of the participants the phenomenon is going to be studied.

Within the choice of the research topic, I decided that I wanted to study parent's experiences about having a child with NLD. The fact that these parents act as translators for these children at the same time, as mediators between these children and other people, make me choose the parents as my participants in this study.

Later, the parents were interviewed both at the same time so that they could give me as much information they could recall making this a rich interview. According to Gall, Gall & Borg (2007), the goal of phenomenology is to describe things as they are and not based upon the participants or the researcher opinions, meaning that both participant and researcher need to "bracket their understandings and seek to discover things themselves as they are directly experienced." (p. 496) The goal will not be to describe things as we automatically remember

from past experiences, but to understand the essence of the phenomenon “from the unique experience of the individual”.

Afterwards, the data was analyzed: I first divided the data in pieces and later searched for meanings. After this process, the findings were synthesized. The couple was understood as one individual, and not as two separate identities, because the aim was not to compare the experiences of the mother and the father. The aim was to have their experience as a couple providing a rich interview when sharing their experiences at the same time.

These experiences were obtained through the use of qualitative interview.

### **3.4 Data Collection Procedures - Qualitative Interview**

Interview is considered to be one of the most powerful ways to try to understand our fellow human beings. (Weiss, 2004; Denzin and Lincoln, 2000; Glesne, 2006; Schostak, 2006; Sinding and Aronson, 2003; Van den Berg, 2005)

Qualitative interview can take diverse forms regarding the nature of *what* and *how* we want to research about. It can be done individual face-to-face, group face-to-face interchange by telephone surveys, email or self-administered questionnaires.

Even though it can be compared to a conversation, interview is not a simple tool of extract information. It will be important not to forget that interviews give us “words with views into different worlds.” (Schostak, 2006, p.1) As pointed out also by Weiss (1994), “qualitative interviews enable us to learn about perceptions and reactions knowed only to those to whom they occurred.” (p.10)

According to several authors (Weiss, 1994; Glesne, 2006; Kvale, 2007), the goal of an interview will be to produce useful information to the research project. This aspect can be closely related to the relationship between the interviewer and the respondent: the interviewer will ask the respondent questions which are related to the research project and not by out of idle curiosity, in the same way that the respondent will accept the interviewer guidance regarding the topics that are need

A qualitative interview can differ in the degree of structure, being categorized as structured, semi structured or unstructured interview. In this study, was used a semi-structured interview.

### **3.4.1 Semi structured Interview**

A semi-structured interview its beneficial when the goal is to explore a certain theme giving the interviewed some freedom when talking about it. The participants can freely talk about their experiences and have some control upon the interview process, however is the researcher who in last instance controls the process and guides it in order to get as much valuable information as possible.

Before the interview was conducted, an interview-guide was prepared in order to help me to conduct and organize the questions during the interview process (see appendix 1). I dedicated sometime reading literature about NLD before writing the interview-guide. This helped me to develop my questions and to search for possible communicational challenges that I could use to elaborate more effective questions. In agreement with Weiss (1994), "Any question that helps the respondent produce the material you need is a good question." (p.74)

In this interview-guide there were no specifications in how to formulate the questions. This tool was only to help me to conduct the interview. The questions were pre-organized in order to control all the process in a clear-cut way. (Denzin and Lincoln, 2000) The questions were open-ended so that I could support the participants to give me long and elaborated answers.

Some notes were taken on the side of the interview-guide, but this was a technique that was not used as a system. It was always my concern to keep a good visual contact with the parents during the interview so it could flow in a very natural way.

The interview took place in the house of the informants in a quiet and peaceful place. The parents could choose where the interview was going to take place, and whether or not the child would be present. The couple's son was not present during the interview because he was at school.



The interview was done in a relaxed context and the fact that we knew each others from before helped to create this relaxed environment but also, a trustful one. The order of the questions seemed to be the most adequate and the information flooded in a very natural way.

The interview took one hour, however after this one was completed; the door was left open in case for the need for more data. The duration of one interview can be related with its structure (easy and sustaining), and also with the cooperation of the respondent. A realistic expectation is that one interview can go for an hour and a half or two hours. (Weiss, 1994)

After the interview was concluded, we dedicated some time talking about how it went and to talk about the member-checking. To have the opportunity to review their information seemed to be a very positive factor, especially when research and researchers don't communicate in their mother tongue.

### **3.5 Validity and Interviewing**

Because qualitative interview is the only data collection technique used in this study, it seems relevant to discuss validity questions concerning the use of this technique. Another factor, intrinsic connected with validity, is the aspect that I had a relationship with the only participating couple, therefore it also seems relevant to discuss the possible weight of this aspect.

Hammersley and Atkinson (1995), refer that it's not possible to eliminate the influence of the researcher, and in qualitative research that's not the aim. The point will be to understand it, and use it efficiently.

These authors claim that the important it's to understand *how* the researcher affects the interview situation and how can this influence the validity of the conclusion made by the researcher from the interviews.

In the same way, Collingridge and Gantt (2008) defend that "measuring what one purports to measure in qualitative research means selecting an appropriate method for a given question and applying that method in a coherent, justifiable, and rigorous manner." (p. 391)

The fact that I had a close relationship with the son of my informants, and because it was also my only informant, made think about techniques that would be necessary to keep the validity of this interview.

My biggest concern was to be biased when analyzing the data because of the narrow relationship with this family. That the fact I was so close to some of the experiences that were going to be talked about, and because I had experienced some of these challenges with this boy, made me constantly aware about not to “take for granted” and to be always open to situations that I didn’t know from before or that I had never experienced and be always an active listener. As point out by Shah (2006),

It is recognized that the closer our object matter is to our own life the more we can expect our own worldview to enter into and shape our work, to influence the questions we pose and the interpretations we generate from our finding. (p. 211)

Authors argue that, even though it’s not possible to eliminate the influence of the researcher, and in qualitative research, that’s not the aim, there are techniques which can secure the validity of an interview.

One of the procedures used was, first of all, to explain this couple that all the information was important, all the histories that they could remember would be very significant for a rich interview.

The interview questions were sent one week before the interview, so that the couple could have time to discuss between them, eventually write some experiences down, etc. Weiss (1994) resumes that our best guarantee of the validity of interview material is to establish a context of a good interviewing partnership.

It was also explained that they would receive the interview after I had transcribing it; so that these could through it and check that I had understood what they have shared with me. This technique is member-checking.

Member-checking, also known as informant feedback, is a technique used to improve accuracy and validity. In recent studies two methods were identified as possible ways to carry out a member-checking: the first one is to send the transcripts to the participants to be confirmed; the second is to send a summary of the analysis.

After I had transcribed the interview, I sent to my informants the transcription of this interview. They were welcome to verify if I had understood the information that was shared with me during the interview process.

Member-checking provides an opportunity to validate the data at the same time that has a contribute when establishing a good and trustful relationship with the informants. Despite the chosen method, member-checking should be done in order to improve quality research.

### **3.6 Ethics in Interviewing**

Kvale (1996) describes an interview as a “moral enterprise” and this has to do with one of the aspects of the researcher’s role. It will always happen a relation of empathy between the researcher and the informant(s) and this seems to be an inevitable fact.

During the interview process, relationships of empathy are created between researcher and informants. This empathy will make the informants experience a close relationship with the researcher and therefore will make them feel more safe when sharing the information. On the other hand, the researcher because of feeling him/herself close to the informants can experience a sense of protecting even more the information that is being shared. However, some authors, like Watson (2009), alert to the fact empathy can be ethically ambiguous and can be perceived simultaneously as a tool and as a goal.

In this perspective, the researcher uses empathy as a tool to be able to reach more information about the participant. Showing empathy with the participants will naturally make them open their self more to do researcher questions. In order words, this is not a casual naïve fact: researcher uses empathy as a tool to get more information about the participant.

Watson also claims that,

It is not that we cannot empathize, but that we do it all too easily, projecting our own understandings onto the unsuspecting other and in the process prematurely closing down research. We should subject our empathic responses to a rigorous scrutiny, be suspicious of empathy, don’t encourage it (it only make it worse). (pg. 114)



In the same way, Glesne (2006) advert s that “a common mistake in interviewing is to ask questions about a topic before promoting a level of trust that allows respondents to be open and expansive”. (p.84)

In relation with this, Denzin and Lincoln (2000), call attention to the fact that even though when this relation of trust happens it is still a fragile situation: any less conscious step given by the researcher can destroy months of already gained trust.

In this way, and in order to provide the possible informants all the necessary information. In the letter that was sent to the parents (see appendix 2), was described the object of the study, the goal, the approximate time of interview, in which language this was going to be conducted, that this one was going to be recorded in order to assure the quality of the information, and that their participation was totally free, meaning that the participants could withdraw at any stage, or to withdraw any unprocessed data they had supplied, they were are free to do so without prejudice.

Miller and Bell (2002) point out that informed consent can be problematic if isn't clear what the participant is consenting and where the participation starts and finishes. According to these authors, informed consent should be “ongoing and renegotiated between researcher and researched throughout the research process.” (p. 53)

### **3.7 Data Analysis Procedures**

#### **3.7.1 Recording the Interview**

This interview was recorded in two different recording machines so that I could have a back-up if something went wrong with one of the devices. According to Kvale (2007) this is the most effective way to document an interview, because the researcher can concentrate in the participants and in the dynamics present during the interview process, while the interview is being taped.

During the interview short notes were taken to help me to remember about certain aspects that were difficult to decode when listening to the tape, such as, for example, the nonverbal

communication between the parents. Kvale (2007) defends that these notes should be short in order not to interrupt the “free flow of conversation.” (p. 94)

After this step, was time to transcribe all the data.

### **3.7.2 Transcribing the Data**

Transcribing data is a vital phase when doing qualitative research. Kvale (2007) calls our attention for two different moments: the moment which occurs during the interview process and the moment which occurs during the transcription process.

During the interview process, and due to its dynamic, all the movements and expressions are available for the researcher, the process is happening in the present. Recording and transcribing that process can be seen, according to this author, as “abstractions” (p. 93): the first abstraction occurs within the recording of the interview. The interview is a lively moment full of vibrant moments, however when these moments are recorded “are not accessible to the out-of-context reader of the transcript.” (p. 93)

The second abstraction will occur during the transcription of the interview, when we transform the previous process into the written form. Here, the “tone of voice, the intonations and the breathing are lost”. In resume, “transcripts are impoverished decontextualized renderings of interview conversations.” (p. 93)

In the same way, Poland (1995) defends that the rigor of transcribing can reveal problematic when it comes to the inter-subjectivity of human communication. Even though feelings can be expressed by words (silence, intonation of voice, etc.), the full flavor of the experience will not be possible to write down, therefore improbable to be fully representative of the interview context.

In this research, transcribing the data material gave me the chance to reflect upon all the information that I, in some way, was expecting to get. As it was referred before, it was always my concern to try to place myself in a position that, even though I knew a lot about this boy’s challenges, I needed to be open and don’t take anything for granted so that I could be surprised!

According to Watson (2006) the present time of the interview needs to be experienced on that same time, but it also needs to be reflected afterwards. Writing the transcription produces a “temporal dislocation” and that factor can produce a new relationship with the data, being therefore necessary to reflect upon this factor.

During the interview, and later during the transcription, I was honestly happy to realize that I was positively surprised with all the data that I got: It was really a new perspective, new information and new facts. This made me confident for the next step: analyzing the data.

### **3.7.3 Analyzing the Data**

Kvale (2007) writes that if the analysis begins after the interview is done and transcribed, then is too late! The process of analysis should start within the process of interviewing through clarification of meanings of what is being said. The interviewer should have the ability to send the meanings back to the participants and try to clarify it in the interview process.

This author states that “The interview researcher is his or her own research tool. The interviewer’s ability to sense the immediate meaning of an answer, and the horizon of possible meanings that it opens up, is decisive.” (p. 60)

During the process of transcription of the interviews, and already thinking about their analysis, memos/notes were written in order to facilitate the analysis process later. This helped me to initiate the process of interpreting the data. This practice, according to Maxwell (2005), helps to develop categories and relationships between the data.

### **3.7.4 Interpretational analysis**

Interpretational analysis can be described as the process of exploring the data in order to find themes, pieces, that later will explain the phenomena under study. (Gall, et al., 2007)

The data will be broken in themes or dimensions, after this the researcher will make deductions about the object as a whole, and here according to Corbin & Strauss (2008) relies one of the challenges: “Without some background, either from immersion in the data or



professional/experiential knowledge, the ability to recognize and give meaning is not there.”  
(p. 46)

Also, according to Blumer, (1969), analysis involves interpretation, meaning that is necessary for the researcher to understand the participants experiences as related by them.

### 3.7.5 Coding the Data

Coding is an interpretive technique that organizes the data and provides a mean to introduce the interpretations of the data. This coding process is more than paraphrasing, is a relation that is established between the researcher and the data. Corbin & Strauss (2008) defends that “involves interacting with data (analysis) using techniques such as asking questions about the data, making comparisons between data...” (p. 66)

During the process of transcribing the data, I wrote notes with possible designations for a certain piece of data. This helped me in both ways: by the time that I was finished transcribing the data, I had already coded some of the data. At the same time, it was very productive to quest about the data since the very beginning of its transcription.

Questioning is considered to be one of the analytical tools that the researcher can make use of during the data analysis. (Blumer, 1969) It will be a useful activity during the all process of data analysis. It will help the researcher to keep connected to the data, at the same time that will help to start the analysis process.

During this process, I experienced a constant questioning about my close relationship to one of the informants and how this could affect my *reading* of their experiences. Even though is necessary a relationship between the researcher and the data, this bond shouldn't affect the capacity of the researcher to “think outside the box” (Wicker, 1985), and this is related to the researcher's ability to not let that preconceived thoughts affect what the data is going to reveal. In the same way that, coding isn't about labeling unprocessed data and used it as a sticker, coding is the skill to think abstract, it requires “searching for the right word or two that best describe conceptually what the researcher believes is indicated by the data.” (Corbin & Strauss, 2008, p. 160)

The next chapter reveals the findings of the interview.

## **4. Presentation of the results**

### **4.1 Characteristics of the Communication**

The parents begin to define the communication between them and their son as challenging but also very humorous:

Mother: *Hmm... it's of course, changeling, hmm... especially when we are comparing with the other children... hmm... it has a lot of humour! Either because... we don't always understand what he is trying to tell us or he misunderstands what we are trying to say... and... that can be... funny in part, for both parts!*

### **4.2 Challenges**

In the same answer, both parents emphasize that it's very challenging to communicate with their soon:

Mother: *But it's quite changeling, it has to be much more aware of what we are saying, aware of all we say, so we have to be much more... conscious of a... communication compared to... communication to the other children...*

#### **4.2.1 Objectivity**

Objectivity appears as the first challenge. The need to be objective and concrete when communicating with their soon seems to be the first challenge to achieve a comprehensive communication:

Father: *Hmm... I think that one difference is that, we have to be so very concrete in all our messages, and... that... that it's very easy to forget, because... because we are not very specific when we are talking to other people... and then he... with him we have to be very precise or... for he not to misunderstandings... or he will not get it at all... or... and it's very, very difficult...*

It seems that the difficulty in being concrete has to do with the fact that when talking to other people there's no need in being so concrete and objective all the time. The fact that isn't something that is necessary to establish a complete communication with others seems to make of objectivity a big challenge not allowing the parents to be consistent all the time:

Father: (...) *it's not impossible, but... we never manage to do it consistently all the time...*

#### **4.2.2 Difficulty in understanding social codes**

The difficulty of the child in understanding social codes is also understood by the parents as a very relevant challenge:

Mother: *Ja, because it's... ja, because all the social codes and so on... they are... how do we say...? We learned them from the start... we don't have to think about it... So it will be the same pattern each day and it will work well with T. because we have to be so aware of what we are going to say and how we are going to say, and we don't have a... instruction that we can just read for one: Ok, it works like this! ... So... its different.*

#### **4.2.3 The biggest challenge**

According to the parents the biggest challenge, when communicating with their son, is for them to be understood by the child.

Mother: (...) *we experience more how he handles... how he understands us... I think!*

Father: *Yes, totally.*

Mother: *Because, of course, we have... we have tasks that we have to... we have another... timing... we have things to accomplish and things to... and it... it brings... some requirements in terms of we get to get ready in that time... that type of worries... he doesn't have it, in the same way, it makes some... at least... so that's... maybe to the great extend our communication with him has some goals, or specific goals that we want to achieve also... while he is more... well, he also has goals, of course... but different responsibility... of course...*



#### 4.2.4 Examples of challenging situations between the parents and the child

Challenges situations between the child and the parents can occur daily and reflect how communication is a complex area.

Father: (laughs) *Very... there was one episode two years ago when we were going to travel, just me and T. It was in the middle of the winter, and it was very... the weather was bad and... things were late... and all these things... and we came to the airport... and I looked at the board and... 'Oh, we are late!' I meant that the plain was late! That... just came of me! And then... I started doing something else, because we were going to Portugal and I... we had to catch a train... so I thought... I could just work with the laptop, and he didn't understand that... 'Why are we not catching the plane?' And (laughs), 'Why are we seating here on the computer?' And this confused him, because he didn't get that, the final message: The plane is late. But that: we are late!*

These situations are a fertile soil to grow up frustration on the child:

Father: *And... that is very difficult... And, of course that he got upset! I didn't understand why he got upset!*

This situation is a good example that these parents needs to be always aware of whats they say and how they say it.

Father: *So... hmm... I think... I think maybe that because... Because, a child of his age would probably understood when I said: 'We are late!' Understood that the plane is late! We are not late!*

#### 4.2.5 Challenges at home with parents and siblings

Also at home, daily challenges can be a regular situation:

Mother: *Anecdotes that we have at table, for instance, the other ones are telling things and T. is always... wondering. When everyone is laughing, he is wondering! On the other hand, we can go to a cinema, and he is laughing a lot when we do not understand why he is laughing (laughs)! So... he... lives things differently.*

The parents refer that even though at home is easier for T. to manage his frustration, these challenges are a constant source of disturbance.

*Mother: Well...the thing is that at home he has a place where he can hide...and...to get away, to have some time to come down, so that's something that we expect when it happens here. He gets the frustration easily out, so some level for (impossible to decode) of behaviour, he has, he such that...he...he hides to a great extent ...It's just between us, and we understand...so the children, and us parents, understand the situation.*

One of the biggest concerns of these parents is the need to always be aware to their son's identity, respect his feelings and give him the space to express himself with or without other people around. Both parents also mention expectations, both theirs and other peoples. These expectations can easily be higher than reality.

*Mother: So, in a way, we accept that he behaves like that... While with other people, we have to take him into account...but we respect him, that's our main concern, respect his feelings and respect his...him in the situation...hmm...ourselves we have to be aware that he's not always at the level that we expect to be, that's something that we need to work all the time. But it might be even enforce...or even...hmm...more...hmm...needed to be aware when there are other people...hmm...around...because the others will have completely different expectations both for him and for us. So it's...hmm...with time we think we are a bit more...focusing on T. needs, and it takes...it's a process, of course, and...but it's...we realize that it's the other people that have to adjust! Somehow, we think a bit like that... So, if it's wrong or right...don't know...it's at least something that we see...we expect other people to understand at some point that he doesn't understand (...)*

The father comments about T. need to have always someone close to him and that this fact by itself is already a big challenge.

*Father: Of course that...that...he(impossible to decode) always need to have someone close to him...and of course that is not what is expected from a 10 years old...he is not very autonomist...so of course that we need always to make sure that one of us is close to him...or at home with him. And ...that's a bit challenging....*

The mother continues saying that his needs are seen as natural by his siblings who don't question or complain about the extra attention that T. needs to better manage his days.

*Mother: I see that the his brothers don't even think about it, but the youngest one, 4 years old, he is accepting, with no problem that, T. is always...has company, at least one of us! While he (the 4 years old) is doing a lot of things alone! So, he doesn't even question...why the brother is requiring all the attention! And of course, when we are travelling, when we went to Portugal, that we stayed at the hotel...instead for sleeping at my parents...they accepted! Of course, that they can complain a bit sometimes...but they accepted and they understand that it is a strategy that helps both him and the family, in a way!*

#### **4.2.6 Examples of challenging situations with others**

Challenging situations with others happen quite often. This can be due to the fact that these others expect more of T., that the parents are not able to make them understand that T. has special needs, or due to the lack of knowledge about NLD. As referred by the mother, some of these people, due to their profession, should have some knowledge about NLD.

##### **At the Doctor**

Here, once more, is clear that these parents discuss techniques in order to facilitate these inter-relations:

*Mother: Yes! Well, to the doctor... or that type of... that is very changeling. I remember in the beginning we were always trying to contact or...discussing about this... that we should contact the doctor before we get there and explain the situation so the doctor could take that into account, because... it often... how do you say it... ? There is a ... conflict... quite often, because... hmm... either... it can be either... the way you telling him things... hmm... if you ask T.: 'Could you please jump in one leg?' Mother: 'Could you do that?' He will not like! He will not do it! He will feel that you are testing him. And he doesn't like to be tested. But if you say: 'Jump T!' Then, he will do it! We have quite a lot of examples like this... so... asking him to do... its... he will not consider it.*



Here is a clear example that it's not only *what* we say to children with NLD, it's *how* we say it:

Father: *He will respond it better if you give him a direct order! Can you kick the ball? No, this will not... but if you say: 'Kick the ball!' He will do it!*

Mother: *So... this is what we usually say to the doctors: give him direct command (laughs), and... hmm... and if they see some kind a childish reaction on T. they usually have a tendency to... to handle him as an older child (impossible to decode)...so, completely fails communication... it's always a challenge... communication with others, with a third person, is always a challenge.*

The following words exemplify a situation during a doctor appointment:

Mother: *There was actually one that completely didn't work! We had to go out of the... office, and we never came there back again. Hmm... so the doctor was telling T. to take off his cloth – that is something that especially he doesn't like... he was at a physiotherapist - and... I tried to tell the doctor... You have to be a little bit more(impossible to decode)...because, he... he doesn't like to... and I was trying to say that he has nonverbal learning disabilities, but of course... this would be need more much explanation then this ...because not everyone... know... Even thou, this was a doctor, a children doctor...for children with special needs!! So, the doctor, when she saw that T. wasn't... coping... she said: 'Ok, so I have to call, to pick my assistant and he will help me to take off your clothes'! And then T. just: Uaaaaaaaaa...just disappeared (laughs)!! So, in the beginning he was trying to hide... something that happens quite a lot... he hides... behind or under the table; then he just disappeared! And when he disappeared, I said: 'Why are you handling him like that? You know he has special needs?' And she says: 'Yes! But this is a matter of education! What kind of education are you giving to your children, to your child?!' (laughs) In the end I just said: 'Ok, I don't want think this is working and I think that will not work if you handling him like that, so we have to go!'*

Even though these situations also happen in the school context, these seem not to be so marked by frustration. However, the parents verbalize, once more, the need to predict and control situations, so that T. can understand and be understood on a better way.

### **At school**

The mother explains that before T. was moved into a special needs class, the challenges were bigger. Now, even though there are some challenges, the situation is better than before.

*Mother: Oh, yes! A little the same. Last year, he was in a normal class... and then we had the same kind of problems with the teacher. So he would... hmm... he would be... very easily upset with the things that she would say. And... hmm... and... well, now they know how to handle him in a much better way... they understand... they, in a way, they are prepared for the reactions, so they try to change the way the things... hmm... so... of course, they do this during the day, it's their job, while we have to do it during the whole day... and... sometimes you... you... just relax... you don't... see it as a task... of course, we are just parents... so... so... you are not in the same way thinking always for... forehand?*

The parents talk about challenges that happened at the doctor's office and also at the school, however, new situations, new challenges begin to happen. T. is growing and with that comes new situations.

#### **4.2.7 New challenges**

The fact that T. is growing brings him and his parent's new situations and new challenges. For these parents the best way will be to talk with T. about all his questions in the most possible natural way.

*Mother: And of course, he is growing and... he is developing and that also brings new challenges for the communication... ja... it can be... interesting...*

T. talks a lot about his future: his ideas, his dreams and what he wants to do and. Some of these wishes are not realistic due to all the fields that NLD can affect. Once more, these parents are responsible to handle it in the best possible way.



*Mother: Preparing for the future! That's what the... it was confirmed from a psychologist: that he wants to make a predictable world for himself! So, he is talking a lot about... So, today he said that he got a girlfriend and that they are going to marry and... (laughs) But it's always to... I am going to have that house, these dogs and that car, and... It's just something that... we have to help him... in... in... hmm... talking in a natural way about these things!*

T. expectations concerning the future are not always reasonable. This is a fact that worries the parents,

*Father: Even though his expectations change all the time... I think that...(impossible to decode)...and that is of course, different. Another 10 year old boy who wants to be a fireman, if he doesn't change his mind, he can probably become a fireman...or a pilot or a policeman, or whatever...And with T. we know that that will not happen...*

At the same time, T. is more aware that he needs more attention than the majority of the children around him. He perceives that his tempo is different.

*Mother: Yes...For example when he realizes that he is different...we were driving one day and the younger brother was saying the name of the club where T. goes to, correct while T. said this a thousand times and did not managed to say it correct...and of course: Why can he say it correct and I can't? So, he realizes that some things are easier for the others...he has become much more aware...and that thing that we were talking about, that it was less conflict with his cousins the last time we were together...he was much more playing on his own...but still, the level of frustration was there and we had to took him out of the situation...he is interiorizing more...the problems...so when he is not getting the frustration out...*

During the interview, it was easy to understand that these parents act simultaneously as translators for T. and from T. to the others.

The next transcriptions will focus on the role of these parents considering their task as translators, their strategies, how they try to manage T. feelings, their own feelings, expectations and personal considerations about NLD.

## 4.3 The role of the parents

### 4.3.1 Parents as translators

The mother begins to characterize her and T. father as “translators in both ways”. This expression is quite clear and shows that these parents need to have an active role in T. communicational relations.

*Mother: We have to be translators both ways, both with children and with adults... (...) Because... it's a challenge...*

Even though these parents recognize the need to act as translators, they also show concerns to respect T. feelings during the conversations, in order not to talk pass him.

*Mother: Well... we often try to say something and if it's not working... because it's not always that works, because... at the moment when it is happening... of course, that we try to... to... respect T. in a way, so that we are not talking... pass him.*

According to these challenges, these parents created (and create every day) strategies to prevail over these challenges.

## 4.4 Parents strategies to overcome the challenges

Communication between the both parents seems to be the first step to create effective strategies. To communicate about possible situations that might occur and about situations that have occurred.

*Mother: And we often discuss after things that happen and we say: Ok, we shouldn't have, like, mentioned! Because if we mention something to T., other children will realise if it's something just... you're just mentioning! It doesn't mean that will happen, or that it doesn't have to happen. But he will confuse it has... it has to happen! So, it's... sometimes we mention something and then we realise that: Ok, we done a mistake! Usually we talk about that: Ok, next time we should avoid mentioning... but... its difficult in daily communication! You only talk about things that will happen and... or... it's very difficult!*

The parents refer predictability as the second strategy to better solve the challenges. At the same time, both parents confess that is not easy to always be one step ahead of possible situations.

*Mother: Because he has a... the problem is that, for us to... handle I guess! To always think about, to always predict things, a thing to predict... it's... a... I guess that is the biggest challenge... (...) It's not simple in communication way...*

In addition, T. struggles to adapt to new situations or to new realities that are different from those he had planned or thought about.

*Father: And it has... all must be specific... you can't mention... vague ideas, or... mention possible plans because he will remember everything. To say: maybe we can do this... and he... and that for him, will happen, and then it's not going to happen! And... he is not very good at changing... or managing chance. When something he believes that will happen, and doesn't happen, that's...he gets very upset...*

The third strategy will be to try to handle T. in the best possible way. To try to distract him from moments or situations that might cause him frustration.

*Mother: So the strategy will be to... distract him, with other thing! Because he can be easily distracted in these type of situations. If you offer him some other thing... then you can get a lot out of him! But you're insisting on the same thing... and that's why education it's very different for us, with T. compared to the other children... like a... how do you call it... ? If you want to... stop him to doing things... that you don't want him to do... it's much easier with other children, because they will stop... after... if you do the same consistently after some time, they will stop... It takes some time... its different from child to child, but with T. ... it will become a bigger problem. And if I show, in different ways, hmm... this situation will distract him... actually.*

Also due to his developing process, T. is himself more aware of these situations. Being the one sometimes to ask to have a “break” from these types of situations.

*Mother: Well, at the same time, he is more aware of... we talk with him more about what strategies for him, or at least to...he realises easier where... when it's Ok to stop. And that is something good! And...so he asks: 'Can we go out for a walk?' Or 'can we get out of this?' So, he, he is a little bit more aware and that helps! What we*



*experienced last holidays, new year, that he wouldn't...hmm...even though the...we didn't expected the level of frustration to be so high...in earlier travels that we had with the family, conflicts with the other children...the conflict with other children it's quite high...hmm...this time there was much more less conflict because he was much more on his own...so much happening around him that...he has difficulties in assimilating all...he uses a lot of energy still, so the frustration is there and at some point...of course that has a meltdown...and we have to get him out of the situation... And then you have this problem: it's that, not everybody around understands...hmm...how serious the situation is! So we, as parents, sometimes we have difficulties in understand him; where we should stop, take him out of this situation; but for others this is much more difficult!*

The lack of knowledge about NLD by other people it was constant mentioned by these parents as an extra challenge.

*Mother: So, other people would probably not even really realise that the situation was so bad, that we really had to take him out of the situation. So...that's of course, a big challenge... It could be challenging of course, with a child without nonverbal learning disabilities with other more concrete...problems, because you just say: 'Ok, he has the hyperactivity!' So everyone will understand! We don't have to explain so much!*

Both parents ended up resuming the strategies:

*Mother: A clear communication, we try to predict, to prepare, avoiding something from happening or... to prepare for... that's not always easy... (laughs)*

*Father: That's very important, predictability... he needs to know what is going to happen... he doesn't handle surprises very well... or changes in his program.*

According to these transcriptions it is easy to understand that all these challenges and strategies also have implications in how these parents try to manage T. frustration.

## 4.5 How parents try to manage their son's frustration

Constant attention to T. humor shape seems to be the first thing to do,

Mother: *You feel that he is becoming more and more restless and then... and then it's just like a domino effect. You are not understanding always why he is restless, and you also get a bit... restless... or... so if... So the tendency for this domino is to escalate.*

T. shape can also influence how he manages possible frustrating situations,

Mother: *(...) and of course that the affect is that it's very dependent on communication... it's a... there are other factors that affecting here... like his mood, if he is tired or not, its affects his learning abilities. We noticed that he (impossible to decode) very easily, and it affects also communication naturally. So its... if he are more relax and so on, much easier we get him to understand what we really want to say, if there is any doubt from his side. But if he is tired he will just... hmm... hang on to this... and its difficult to get him out of the... spiral.*

Try to manage T. frustration it's not a simple task. These parents need to be constantly aware of his moods, which can increase his anxiety, but they also need to be aware of concrete situations that happen outside their home. At the same time, they need to appeal to T. for him to share these situations,

Mother: *And that is difficult, even if we want to try...to talk with him...is not so easy to get him to really engage in such conversation...so it's....and we are always learning! When he started in this class, he start telling in the school that he was dumb...stupid because he was starting there and the people that work there were very concerned about this...and try to tell him: 'You're not stupid, you can do this, and you can do that...!' And the talked with us and we did exactly the same, then we talked to his psychologist and she said: 'Don't try to underestimate...make it less, because he has frustration that he has to come out, and you need to confirm this frustration...' And of course, that we need to do that!*



Further, the father also mentions that his shape can have a direct influence in how he perceives what is happening around him, and that this situation can lead to higher stages of anxiety,

*Father: (...) sometimes he just completely misunderstands everything and that happens when we are communicating to him... if he is tired or whatever... and then just builds on frustration, and then he will...and sometimes it's also very difficult to predict... not always we manage to diffuse him or taking him out of a situation before that happens... if usually... hmm... he is more susceptible to have a meltdown than a shutdown, he gets very frustrated, he will just overload.*

These situations are cause of big stress not only for T. himself but also for the parents:

*Father: And that can be very changeling too. And... sometimes it happens... and I don't understand why... just happens. And... and sometimes we think that we manage to diffuse him to calming him down, and then we go and... and then he is back in... and just continuing ... it's very difficult to understand, very difficult to handle it...It was easier probably because he could just do something else, he would be (impossible to decode) and it would be ok, and sometimes we could go back in... for example before we could distract him with something, take him away from it, and then he would calm down, and now( impossible to decode)we can take him away... but then he will go back in... he is at the same point at where we left him...*

According to these transcriptions, these parents try to be always aware and, once more, try to predict situations that might cause their son frustration. Even though both agree that it's not every time that they are able to predict or distract him from these states, the fact that both of them need to be constantly aware can drop the number of challenging situations.

Intrinsically connected to T. feelings are, of course, the parent's feelings.

## 4.6 Parent's feelings

When questioned about their responsibility every time that communication between them and T. is not well succeeded, the parents show no hesitation in assuming all the responsibility,

*Mother: Yes, hmm...yes, of course! We...feel that...in terms of responsibility. He has no, he has limitations in what he can do in terms to improve the communication...so, of course, that we have to...we have to...be responsible for the communication when doesn't work, when it's not working between us and T.*

The father agrees without hesitation:

*Father: Of course, I do! (laughs) But I don't know what to do often!!! (laughs) He can't be responsible!*

The mother proceeds explaining even though they sometimes expect more of T. (in a developmental perspective way), it is their responsibility to make sure that communication between them and T. is well succeeded. Once more, the parents mention the fact that they are translators,

*Mother: Ja...probably because we are always hoping that he grow up and that he is learning and that he is...that hope is always a bit to...to ahead in terms of his development! So...there's always an adjustment, all the time, and of course that we feel responsible if ...it's our responsibility, we have to try to understand him, and try to help him...hmm...it happens also we are communicating with a third part: we feel that we have to...hmm...to make the others understand some of the things that T. is trying to say...hmm...and the other way around! We have to help T. to...so it's kind of a translation!*

These parents also assume full responsibility when it comes to their own physical and psychological condition: recognize that their shape can influence the more or less comprehension when talking to their soon.

*Mother: And of course that one thing is his level of frustration and our days are not...if we are more tired and so on...then you will have less patience...so your level of understanding is probably lower...and of course...that's not easy...*

The parents' feelings can also be translated into their expectations.

## 4.7 Parent's expectations

The parents refer that even though they have present that they need to have especial attention when talking to T., sometimes they expect T. to be in an upper level, regarding, for example, topics that were discussed in the past. This is a natural expectation considering that human learning processes is a constant construction of experiences, however, in this case, former experiences seem not to help to construct a solid and applicable knowledge .

*Mother: (...)...because the fact that he has a bad day, that he is tired, then the learning will be affected, quite a lot! So the memory, even the memory, what he learned on the previous day, then...everything is gone! If he has a bad day! That's very difficult to understand for...even for us parents, because it's a natural evolution of children: to learn, you are curious, you are...a lot of things in learning that are very atypical for NLD...very atypical...and the expectation that in one day he can actually manage something then you will apply this new knowledge in new things, in a new area and...that it's not there...so, so...it's so unnatural in a way...not intuitive... This is probably the biggest challenge, I guess. For example, if you are teaching something, if it is like a physical activity, you have to talk to him to teach him to kick the ball! If you're showing him mimics or movements, which are visually, he will not catch it! And that is so...so little intuitive...if you should explain, explain wit verbal...how you're going to kick the ball...(laughs) So, I understand the frustration of the teachers, and the problem is that every time he changes teacher, it takes about 3 months for the teacher get to know T.*

The parents also shared their expectations, many times worries, concerning his future:

*Mother: Yes, because we noticed that he started to be more aware of his difficulties, hmm...then he also got a bit more...hmm...less confident and more tense because of the situation...so of course, how he developed with the years, with the difficulties, even though I was afraid that it was going to be worse, that it was going to be...so I think that we are always a bit more concerned or more negatives...then what happens...I don't know... One of the things that we have been told, all the time is that...it's expected that he will get all these psychological problems...so...of course, it makes us...a bit negative about his future...*



*Of course that he has a lot of expectations, unrealistic expectations about his future, and that is something that of course...can be a bit worrying...in a way it's good that he is positive about the future...but when he realizes that he can't...that he probably will not be able to have 3 cars (laughs), or that...things will not be that easy...*

Among these worries, is the fact that NLD is still unfamiliar to a lot of people.

#### **4.8 Parent's feelings regarding the awareness about NLD**

Comments about the lack of knowledge about NLD were a constant during this interview. The parents comment the fact that NLD, contrary to other learning disabilities, is still unknown for the majority.

*Mother: If we say: 'He has nonverbal learning disabilities!' People will just... (laughs), not really...understand!*

This can be a worrying fact. According to these parents, NLD is more common than people think and it's often connected to other disabilities. This is a factor that can disguise NLD, but at the same time, it alerts for the need to comprehend and discuss NLD.

*Mother: There is quite a percentage of children with NLD and it is interesting because we started a group for parents with children with special needs at the school where our children are going, and...at some point we were 15...15 parents of 15 children. And, even though the difficulties were autism, Tourette Syndrom...quite a lot of these had NLD!*

Also in this context, these parents plan and apply strategies in order to provide a safer and comprehensive reality for T.

*Mother: One of the things that we thought about doing (...) this was before we just got the special school, but, was to write a report ourselves with all the things that you can expect from T. and what is the reality! So this was one thing that we were going to do. And this was one thing that when we present it, when we talked about this, at the parents meeting...and...we got this very good hint: just tell them how their children is going to experience T.! Just tell them how their children are going to experience T.*



The father defends that it's important that teachers have knowledge about NLD, so that they also can manage T. in a better way,

*Father: Sometimes he gets to manage everything in one day, the other day he can't manage anything at all, so....he gets frustrated, the teachers get frustrated...*

According to the interview data, it is possible to summarize the challenges and the strategies mentioned by these parents.

## **4.9 Findings review**

Objectivity comes as the first challenge. The need to be objective and clear as possible, in order to facilitate communicational interactions between the parents and their son. A clear communication, in this specific context, means that reality must be explained in a very pragmatic and objective way. This encloses two aspects, that reality needs to be explained in a verbal way, and that this way of explaining needs to be as concrete as possible. Children with nonverbal learning disabilities struggle to make sense of nonverbal communication; consequently, verbal communication will be used to explain reality.

The parents mentioned the difficulty in understanding social codes as the second challenge. This situation can have a severe impact when it comes to process information. Some of these social codes are not spoken codes. We assimilate them during our developmental process, we used them every day, but it is something that we don't need to talk about it in order to it. Some of these social codes are instinctive, guided by our social *antennas*.

A child who is not capable to read social codes, to decode social nuances or to instinctively respond to diverse social contexts, will struggle to have satisfying social relationships and to process information.

The biggest challenge mentioned by the parents was the difficulty of their son to understand them. Even though these parents use several strategies to establish a more effective communication with their son, the challenges are present every day. This fact can be interesting because it can help to proportionate the challenge: if T. struggles to understand his

parents, parents who use strategies and who have a deep knowledge about NLD, it's therefore, secure to presume that this challenge grows extremely when talking to others.

New challenges arise every day. T. is growing and that also means new challenges. Throughout the all interview it's easy to understand that these parents experience challenges and try to apply strategies on a daily basis.

A good communication between the parents is indicated as the first strategy. In order to work together to make of everyday a safe day for T., these parents need to discuss about the challenges and the strategies to use.

The ability to plan, predict, situations is understood as the second strategy. These parents need to be constantly aware to be able to anticipate possible challenging situations. They plan strategies to use in situations they know it going to happen (doctor's appointments, etc.), but they also need to discuss possible strategies which may happen due to a certain situation. Intrinsically connected to this strategy, is their role as translators.

The third strategy used by these parents is to assume the role of a translator; they decode the information for and from T. They decode the information that T. is receiving and help him when he talks to other people. Also here, is easy to understand that this is a continuous task.

In the next chapter I discuss some conclusions and show the limitations of this study.

## **5. Discussion, and the overall conclusions of the research**

This qualitative research has identified several challenges and techniques used by a couple of parents with a child with NLD, in order to optimize communication between them.

This research was primarily designed to be a qualitative study about three couples of parents of children with NLD. After two couples have refrain from participating, I ended up with one couple, who was also my key-informant.

When I decided to write about NLD, I felt that not only I was going to research about a topic that I personally like, but also, that I was contributing to the awareness of a syndrome which is unfamiliar to many people.

I have to confess that when my possible participants, except from one couple, gave up from taking part on this research, I felt disappointed. I felt that this research could give voice to a syndrome so unknown to so many people. This research could also bring knowledge and awareness to the nonverbal learning disabilities field. As I discuss on chapter 3, the reasons might be connected to language barriers or due to the fact that these parents could think that this research would, somehow, compare their answers.

My curiosity and the wish to learn more about this field pushed me forward and the research proceeded with one couple to interview. During the interview process I felt that I had good material to write about these parents experiences. The examples given were quite illustrating of the possible challenges when talking to a child with NLD, and the techniques used by these parents show the need to predict and anticipate possible situations that might happen.

This interview showed that these parents struggle every day in order to proportionate their son a more comprehensible and safer world. Besides having to anticipate possible situations, these parents also need to act as translators: when other people talk to their son and when this one talks to other people. Between this relationship, there's a line that both parents mentioned: the respect for T. identity and the need to be aware in order to not talk pass him. This is a balance that these parents need to be aware on a daily basis.



Throughout the whole interview it was easy to perceive that parts of the challenges are due to a lack of information about NLD. This fact contributes to make of NLD an unknown condition. This is a worrying fact because nonverbal learning disabilities are quite present in many school classes and homes. The fact that professionals working in the field on special needs education, don't know what NLD is or what it may cause (as mentioned by the parents) it's a worrying situation.

It is necessary more research within this field so that NLD can become more visible and understandable. And, at the same time, can achieve its own identity as a unique syndrome with its strengths and deficits. The fact that it's often associated with other conditions, can make it difficult for recognize it as a singular syndrome.

At the same time, is need more research about communication and NLD. Because children with NLD are extreme verbal and possess excellent skills when it comes to verbal communication, this field is often neglected. However, these skills are not effective as they may seem. These verbal skills are often the ability to repeat information and not the ability to process and understand it.

It's our role as special needs teachers to make of NLD a more understandable disorder. To make it more discussible and therefore, more visible. The everyday of many children is influenced by the characteristics of NLD. As teachers, is our role to make the school the safest place for these children.

This research is the starting point for further studies about NLD.

## **5.1 Limitations of the research**

Being a qualitative study, this research carries limitations when it comes to the generalization of the findings.

These findings can't be generalized to other situations, however, at the same time, that is not the aim. The aim will be to show the informants perspectives and feelings according to their experiences. These experiences, being singular, can't be generalized to others or as ways of conduct.



However, the fact that the findings of this study rely in just one interview, can be seen as a limitation. Even though the experiences are singular and the intention was never to compare them, this study would be able to show in a more significant way, challenges and strategies concerning NLD, if it could rely in two more interviews.

These findings might be subject to other interpretations, according to Punch (2005) the “more difficult problem concerns the correspondence between verbal responses and behavior, the relationship between what people say, what they do and what they say they do, and the assumption that language is a good indicator of thought and action.” (p. 176)



## Appendix 1

### Interview - Guide

1- How old is your child and how old was he/she when was diagnosed with NLD?

2- How do you experience the communication between you and your child?

3- What do you experience as the biggest challenge in the communication between you and your child?

4- Can you describe any particular situation where communicating with your child is more challenging? Can you give me concrete examples/ tell me a history?

\*4.1- Can you tell me, for example, school situations where communication between your child, peers and/or teachers reveals challenging/difficult?

\*4.2- Can you tell me, for example, situations at your child's doctor where communication reveals challenging/difficult?

5- What do you do to overcome these challenges?

6- In your opinion, which tactic/approach works better when communicating to/ with your child?

- At home

- At school

- At doctor's place

- ...

7- Does your child become frustrated because of these episodes?

7.1- (If yes, to frustration) Does the place where these episodes happen, at home or at a public place, have the same influence in your child's frustration?

7.2- (If no, to frustration) In your opinion, what feelings do your child deals with, when these episodes happen?

8- Do you feel responsible if the communication between you and your child is not well succeeded?

8.1- (If yes) Can you explain me why?

9- Do you experience that you, and yours child's siblings, need to adapt your everyday (private and social context) in order to meet his/her needs?

10- What do you think it should be done in school and in society in order to improve the quality of life for children with NLD and their parents?

11- As parents, what concerns you most about your child's future?

\* Support questions



## Appendix 2

### Research-project:

**“Children with Nonverbal Learning Disabilities: what kind of communication challenges do parents face and which strategies do parents use to overcome those challenges.”**

Dear Parents,

You are invited to participate in a research-project which is being conducted Ms. Alexandra Ramos (Master Student), and supervised by Professor Peer Møller Sørensen of the Department of Special Needs Education at the University of Oslo.

This research is interested in understand what kind of communication problems may arise in daily interactions between children with NLD and you parents, and what kind of strategies do you use to overcome these challenges.

I am asking you to participate because I believe that your experience as parents of a child with NLD would help me to better understand what kind of communication challenges may arise between you and your child in daily interactions, and also to understand which kind of strategies do you parents use to overcome those same challenges.

6 participants will be enrolled in this study (3 couples of parents). Should you agree to participate, you will be required to participate in one semi-structured interview, in English, that will last approximately 1, 5 hour.

With your permission, the interviews would be tape-recorded so that I can ensure that I make an accurate record of what you say.

All information will remain totally anonymous.

Please be advised that your participation in this study is completely voluntary. Should you wish to withdraw at any stage, or to withdraw any unprocessed data you have supplied, you are free to do so without prejudice.

Signature (s):

Date:

Thank you, for your cooperation.

If you have any questions about the study, please feel free to contact:

**Master Student**

Name: Alexandra Ramos

Phone number: [REDACTED]

Address: [REDACTED]

[REDACTED]

E-mail: [REDACTED]

## Appendix

Norsk samfunnsvitenskapelig datatjeneste AS  
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Postboks 1140 Blindern  
0318 OSLO

Vår dato: 30.03.2010

Vår ref: 23905 / 2 / MAB

Deres dato:

Deres ref:

### KVITTERING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 28.02.2010. Meldingen gjelder prosjektet:

23905

*"Children with Nonverbal Learning Disabilities: what kind of communication challenges do parents face and which strategies do parents use to overcome those challenges."*

Behandlingsansvarlig  
Daglig ansvarlig  
Student

Universitetet i Oslo, ved institusjonens overste leder  
Peer Møller Sørensen  
Alexandra Ramos

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i melde skjemaet, korrespondanse med ombudet, vedlagte prosjektvurdering - kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, [http://www.nsd.uib.no/personvern/forsk\\_stud/skjema.html](http://www.nsd.uib.no/personvern/forsk_stud/skjema.html). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/prosjektoversikt.jsp>.

Personvernombudet vil ved prosjektets avslutning, 31.08.2010, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Bjørn Henriksen  
*Knut Skjelt*

Marte Bertelsen  
Marte Bertelsen

Kontaktperson: Marte Bertelsen tlf: 55 58 29 53  
Vedlegg: Prosjektvurdering  
Kopi: Alexandra Ramos, Fougstads gate 47, 0173 OSLO

Avdelingskontorer / District Offices:

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